

AIDS AND AGING WORKGROUP: ACTIVITIES AND RESEARCH ADVANCES

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Significance of Program Activity

Since 1987, the National Institute on Aging has spurred research to understand the influence of AIDS in an aging society (Riley, Ory, and Zablotsky, 1989). The degree to which HIV/AIDS has affected older people has received scant attention in the U.S. despite the fact that in 1997, there were more cases of AIDS among older people than children under the age of 5 (8530 cases vs. 6343 cases). The face of HIV/AIDS is likely to change in the future. The HIV/AIDS caseload is aging with new treatments decreasing mortality rates for those already infected and a disproportionate growth in new cases among the fifty plus population.

Program Activities

With the establishment of a NIA-wide Workgroup on AIDS and aging, this area of research has become an Institute-wide priority. Several activities have been undertaken to stimulate research in this area: 1) in 1997, NIA also sponsored a research synthesis and agenda setting conference on AIDS Prevention and Care Research to identify the most promising research avenues; 2) in 1997, NIA spearheaded a new trans-NIH program announcement on Behavioral Sciences Issues in Prevention Research, 3) in 1998, NIA participated in the trans-NIH RFA on human immunology and AIDS issues (two will be funded), and 4) NIA now lists AIDS research as a focal bullet in its small grant program to provide needed pilot testing and intervention development (three new projects were funded in FY 1998). The NIA AIDS and Aging Brochure which describes current research activities and priorities in the behavioral and social sciences has been updated. Workgroup members (both extramural and intramural) have also submitted proposals to OAR/NIA for FY 2000 funding.

Research Advances

Increases in AIDS caseload points to the importance of targeting the older population for HIV/AIDS prevention and care. Despite being one of the fastest growing segments of the AIDS caseload, persons 50 and older have largely been ignored in both scientific studies and intervention efforts. Ory and Mack reveal that the traditionally cited 10% figure (10% of the AIDS caseload has been 50 plus since the beginning of the epidemic) is actually an undercount of the impact of the epidemic on middle-aged and older persons. New analyses reveal that 15% of the living caseload is now 50 plus, despite reports of a shorter post-diagnosis survival time for older adults (Justice, K01 AG00826). This suggests a graying of the AIDS caseload which is further supported by recent a recent CDC report documenting that new cases actually rose twice as fast in the older population as compared with the younger population for the period of 1991-1996 (22% versus 9%). These findings point to the critical need for additional

research on the contextual influences on HIV/AIDS risks for older people and effective strategies for reducing such risks. Also important is a better understanding of how older people, once infected, seek and receive treatments, and the extent to which age affects health professionals' diagnosis of and treatment recommendations.

Older people's common sense model of illness may lead to delays in getting tested and seeking treatment for HIV/AIDS. Despite behaviors that placed them at risk for HIV/AIDS, older people often fail to recognize their vulnerability and attribute symptoms to other illnesses or age-related changes (e.g., hypertension, menopause). Even when tests identify them as sero-positive, some do not seek medical care because they feel healthy. When they do experience symptoms they think might be AIDS-related, older people express concern about their ability to differentiate symptom cause from aging processes, the HIV infection or some other co-morbid condition. These findings are particularly problematic since current consensus on treatment effectiveness suggests treatment must begin as early as possible. More concerted efforts must be made to elucidate the public about the importance of recognizing risky behavior as the impetus for seeking testing and treatment rather than waiting for the onset of symptoms. Greater attention must also be made in sensitizing and educating health care providers to the particular problems older people who are at risk have in trying to attribute cause to the various symptoms they may experience. (Siegal, R01 AG13379).

In comparison to younger caregivers, older caregivers of persons with AIDS (PWA) seem better able to draw upon personal and social resources to help them manage caregiving demands. Older caregivers are less likely to experience feelings of overload, frustration and depression. In comparison to other groups, mothers do not appear to be more distressed with caregiving responsibilities but do tend to remain more preoccupied with memories of the deceased even after 4 or more years of bereavement. These findings suggest the need for broader conceptualizations of the caregiving experience to examine how life course factors affect the caregiving relationships and subsequent outcomes. Causal factor explaining the differences between younger and older caregivers have not been clearly identified, although several reasons can be suggested (e.g., generational expectations about caring for those in need, life stage issues related to illness and, the stigmatization associated with this particular illness and mechanisms for coping). Research in this area provides important opportunities for broadening our understanding of the caregiving experience by identifying variation in caregiving meanings and styles among groups and examining the extent to which differences are influenced by social and historical factors (Mullan, R01 AG12910).

Future Directions

Research in this area is important because it is not singularly focused on epidemiological studies to identify the extent to which the problem has affected various groups of older people. It requires a blend of qualitative and quantitative methodologies that are theoretically-driven to identify and understand (a) who is at risk and determine how these health and behavior determinants are influenced by age, gender, race and life course differences; (b) the social, psychological and behavioral implications of HIV/AIDS on

the person with AIDS (PWA) and family and friends who provide assistance, and; (c) the extent to which health care services are available and accessible to and used by the older PWA. There is also a need to advance research knowledge in the development of interventions that incorporate educational and behavioral change strategies to increase age-related knowledge about AIDS, reduce risky behaviors and encourage older people to seek testing and medical treatment sooner rather than later, as well as to enhance medical and social supports for those in need. Complementing this emphasis on behavioral and social research, NIA is also establishing priorities for research in the clinical and biological sciences.

References

Centers for Disease Control and Prevention. 1997 "Update: Trends in AIDS incidence, deaths and prevalence—United States, 1996. Morbidity and Mortality Weekly Report 47(2): 21-27.

Centers for Disease Control and Prevention. 1998 "AIDS Among Persons Aged >50 Years—United States, 1991-1996." Morbidity and Mortality Weekly Report; 47(2), 21-27.

Justice AC, Weissman S. "The survival experience of older and younger adults with AIDS: Is there a growing gap in survival?" Research on Aging. Forthcoming November 1998.

Mullan JT. "Aging and informal caregiving to people with AIDS." Research on Aging. Forthcoming November 1998.

Mullan JT. Bereavement adaptation and domains of mastery among AIDS caregivers. Paper presented at the Gerontological Society of America, Cincinnati, OH, November, 1997.

Ory MG, Mack K. "Middle-Aged and Older People with AIDS: Trends in National Surveillance Rates, Transmission Routes, and Risk Factors." Research on Aging. Forthcoming November 1998.

Pearlin LI, Mullan JT, Semple SJ, Skaff MM. "Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist 1990 30, 583-594.

Pearlin LI, Aneshensel CS, LeBlanc AJ. The forms and mechanisms of stress proliferation: The case of AIDS caregivers. The Journal of Health and Social Behavior, 1997 38(3): 223-236.

Siegal K, Schrimshaw EW, Dean L. "Symptom ambiguity among late middle-aged and older adults with HIV. Submitted for review to Research on Aging.

Siegal, K. "Symptom interpretation and medication adherence among late middle age and older HIV-infected adults". The Journal of Health Psychology (in press).

Siegal K, Schrimshaw EW, Dean L. "Symptom interpretation: Implications for HIV-testing and treatment initiation among HIV-infected late middle-age and older adults. Submitted for review to AIDS Care.

Wight RG, LeBlanc AJ, Aneshensel CS. "AIDS caregiving and health among midlife and older women. Health Psychology 1998 17(2): 130-137.